

## The Golden Freeway: a preliminary evaluation of a pilot study advancing information technology as a social intervention for boys with Duchenne muscular dystrophy and their families

Jennifer Soutter<sup>1</sup> BSc PhD, Neil Hamilton<sup>1</sup> BA Dip BA PGCE, Peter Russell<sup>1</sup> BA, Chris Russell<sup>1</sup>, Kate Bushby<sup>2</sup> MD FRCP, Patricia Sloper<sup>3</sup> BA MA PhD and Kim Bartlett<sup>1</sup> BSc PhD FRCPCH

<sup>1</sup>Department of Child Health, University of Newcastle upon Tyne, Royal Victoria Infirmary, Newcastle upon Tyne, <sup>2</sup>Institute of Human Genetics, International Centre for Life, Newcastle upon Tyne and <sup>3</sup>Social Policy Research Unit, University of York, York, UK

### Correspondence

Professor Kim Bartlett  
Department of Child Health  
Royal Victoria Infirmary  
Queen Victoria Road  
Newcastle upon Tyne NE1 4LP  
UK  
E-mail: kim.bartlett@ncl.ac.uk

### Abstract

Established information technology was used in an attempt to reduce social isolation by providing each family who had a child with Duchenne muscular dystrophy with a personal computer, and e-mail and Internet connectivity. Seventy-four of the 88 families in the north of England (i.e. Cumbria, Durham, Northumberland, Teesside, and Tyne and Wear) with a boy with Duchenne muscular dystrophy who was diagnosed before January 2000 had the equipment installed. Evaluations of equipment usage and parental perceptions of the project were carried out at 3 and 12 months post-installation. Results from quantitative and qualitative interviews with parents indicated that benefits accrued to the families and to the boys themselves: family relationships can be extended, and the boys can acquire a degree of independence which, according to parents' views, can boost self-confidence and self-esteem. As hoped, social isolation was felt to have been reduced, and an occupation, interest and enjoyment provided. The greatest use of the computer was for schoolwork with siblings sharing in this. Cost proved to be a problem for a number of families. For the project team, there were unexpected aspects: creating an e-community was more difficult than anticipated, more training was required and not all families would ever use the equipment to its fullest. However, families did emphasise the value of the project as a way of opening the world for their sons.

**Keywords:** communication, Duchenne muscular dystrophy, information technology, social isolation

**Accepted for publication** 13 August 2003

### Introduction

Under the 'Quality Protects' initiative (Department of Health 1999), meeting the needs of children with a disability and their families was prioritised to include the provision of more and better family support to help these children and their families live ordinary lives. The importance of social inclusion was also emphasised. The Golden Freeway project was conceived as a means of ameliorating the profound isolation experienced by some families who have a child with a life-limiting

illness. In 1998, a partnership was established between the Department of Child Health, University of Newcastle upon Tyne, The Children's Foundation (a registered charity), and Newcastle City Council to consider the advantages of computer ownership and access to the Internet for families with a children with a disability.

Problems for people with disabilities and their families have been identified elsewhere, many of these being social; for example, relationships, family roles, isolation, boredom, loneliness, lack of social interaction and lack of recreation (Blaxter 1976, Toombs *et al.* 1995).

Physical impairment can be viewed as a social stigma and can lead to feelings of social isolation (Emery 1993) because society imputes many negative meanings to a visible physical impairment.

Children with a chronic illness are three times more likely to have psychiatric disorders, and are also at risk from problems of social and school adjustment (Cadman *et al.* 1987, Davis 1993). It is recognised that children with disabilities are limited in their activities in the community through environmental constraints, and limited in access because of wheelchair use, with the result that their daily activity pattern is less varied and they experience more social isolation (Law & Dunn 2001). Older children with disabilities tend to spend more time watching television and are five times more likely to be socially isolated than children without a chronic illness (Cadman *et al.* 1987). However, family life plays an extremely important part in the lives of people with disabilities (Bach *et al.* 1991).

Duchenne muscular dystrophy is a muscle wasting condition which affects only boys. It is a genetic condition arising from a defect of a single protein in muscle fibres, dystrophin. Physical impairment increases over time: a boy will first show signs of the disease when he starts to walk; by approximately 10 years of age, he will need to use a wheelchair and other equipment. As the condition progresses, there are surgical procedures which can ameliorate the condition, such as spinal fusion. At any one time, there are about 1500 boys with the condition in the UK; approximately 100 boys are born with it each year, giving an incidence in the general population of about one in every 3500 male births (Muscular Dystrophy Campaign 1999).

Older boys with Duchenne muscular dystrophy are significantly more likely to suffer from a depressive disorder (Firth *et al.* 1983) and to perceive themselves as having poor peer relationships than boys with non-Duchenne muscular dystrophy (Fitzpatrick & Barry 1990); they tend to become more withdrawn, depressed and isolated (Fitzpatrick *et al.* 1986). It may be that older boys perceive they have a lack of control of their life; it has been considered for some time that a consequence of perceiving that outcomes in life are uncontrollable is a contributory factor to depression (Abramson *et al.* 1978). A feeling of isolation may also result because of the boy's physical disability and perhaps because of the intellectual impairment which is known to affect some boys with Duchenne muscular dystrophy (Bushby *et al.* 1995, Benony *et al.* 1996). Parents do perceive their sons as having psychological problems or being solitary (Buchanan *et al.* 1979, Benony *et al.* 1996).

Ingersoll (1989) defined adolescence as 'a period of personal development during which a young person must establish a personal sense of individual identity

and feeling of self-worth which include an alteration of his or her body image, adaptation to more mature intellectual abilities, adjustments to society's demands for behavioural maturity, internalising a personal value system, and preparing for adult roles'. It is a stressful time for all. For the older boy with Duchenne muscular dystrophy and his family, the stages of adolescence are experienced at a time when the young man is becoming more dependent and it is a time when boys with this condition may experience loneliness (Robins Miller 1991). It is recognised that dependency on others and lack of personal privacy will cause more stress (Emery 1993). Self-determination and independence are factors which can improve adolescent mental health (Zajicek-Farber 1998).

Access to the Internet is increasing at an unprecedented rate; however, in the North-east of England, the rate of home access to the Internet is one of the lowest in the country. At the beginning of the present project (1999), such access was available to just 14% of the population overall, compared to England at 20% and the whole of the UK at 19% (Office of National Statistics 2000). Although these figures have increased, at the end of the project (March 2001), the ranking remains the same: North-east, 32% (the lowest in England); North-west, 38%; London and South-east, 48%; and the UK as a whole, 40% (National Statistics 2002). Internet-based networks enable access to a number of different resources, including: increasing the number and frequency of social contacts, interacting on a one-to-one or one-to-many basis, as well as acquiring timely and relevant information (Shank *et al.* 1999). Not having access to the Internet compounds the existing problems of social isolation and lack of access to information.

The aim of 'The Golden Freeway' project was to investigate the use of the Internet in the home as a means of support and communication for children with life-threatening or life-limiting conditions and their families in the Northern Region. Although access to the Internet and e-mail, and the skills necessary to make use of such access, are a prerequisite for the successful delivery of services electronically, there are two additional requirements. First, the service providers, whether commercial or statutory and non-statutory agencies, must have electronic services of sufficient maturity to be useful to the general public. Secondly, in view of the now overwhelming amount of information and facilities available, some sort of selective filter of the electronic world is necessary, particularly for the novice user. Therefore, a website was created as part of the project. Links to services of direct relevance to the users were put in place, and these were added to as the project progressed and more service providers became available.

The objectives of the present study were: to explore the potential of information technology in reducing social isolation by enabling boys and their families to use e-mail to maintain social contact with others; to provide a variety of information and services of particular relevance to such families in a readily accessible way; to enable parents to exchange information on, for example, locations and services with genuine wheelchair access by creating a parents-only mailbase, a swap-shop and a message board; and to examine the feasibility of promoting joined-up services across both statutory and non-statutory agencies.

## Subjects and methods

### Study design

The population of all families with a boy with Duchenne muscular dystrophy was selected because of its homogeneity, at least with respect to the condition. Since all families are confronted with the same challenges with regard to the progressive nature of the disorder, their requirements for support from statutory and non-statutory agencies are very similar. However, in a cross-sectional study of this nature, since each boy would be at a different stage in the progression of the disorder and hence disability, it was necessary to adopt a mixed study design which included both qualitative and quantitative methods. Given the preliminary nature of this pilot, there was an inevitable compromise in respect of analytical power.

### Study population

The criteria for inclusion in the study were that the family should have a boy (of any age) with Duchenne muscular dystrophy who was diagnosed before January 2000, and that they should live in the north of England (i.e. Cumbria, Durham, Northumberland, Teesside, and Tyne and Wear). Throughout the present paper, the terms 'mother' and 'father', or 'parents', are used to refer to the adult carers; [...] indicates the name of the boy.

### Ethical approval

There was no experimental intervention, nor was there a control group: every family who so wished was involved in the project. The present authors consulted with the then chair of Northern and Yorkshire Multi-centre Research Ethics Committee (MREC) as to the necessity of obtaining ethics committee approval. His advice was that the project was 'an audit of how the Internet connections are used', and hence, did not require formal ethical approval.

### Informed consent

A brochure giving full details of the project was given to every family. Additionally, the consultant responsible for the medical care of these families discussed the project with families when they attended the Muscle Clinic. The family care officers (Muscular Dystrophy Campaign) were involved and also provided further information. At the initial interview, the evaluation process was explained to each family; it was made clear that they were free to withdraw at any time. Permission was sought from each family to use data from the qualitative interviews.

### Recruitment

The project was launched in December 1998. Each family was invited to participate by post and was sent information explaining the nature and objectives. Out of the 83 families known at the outset of the study, 50 families (60%) responded within 3 weeks, registering their interest in the project, and each family was invited to a public event hosted by the City of Newcastle with formal recruitment beginning in June 1999 (a further five families were diagnosed during the course of the project). The 26 families who attended the public event were invited to participate in focus groups, the objectives of which were to identify the key areas of relevance to the families as a whole, the affected boys and to other individual family members. The information gathered was used to inform the design of the website. Subsequently, those families who had not attended or responded earlier were contacted again and invited to become part of the project.

### Equipment and website

All 79 families who had expressed an interest in the project were provided with a personal computer connected via a telephone modem to the Internet. Each boy was assessed at the initial interview with respect to the need for an assistive device, such as a modified keyboard or a tracker ball rather than a mouse, as necessary. The computer was configured to connect to an Internet service provider; an e-mail account, and an ID and password to allow access to the private section of the website were provided. The equipment was installed and maintained, with ongoing support for users, for a period of 2 years by a member of The Golden Free-way team. At installation, some rudimentary training was given. Although the above were provided free of charge to the families, the telephone charges incurred were the responsibility of each family, as suggested by the focus groups. As the project progressed, it became apparent that the issue of cost was one of importance to

10 out of the 72 families interviewed at 3 months and to 16 out of the 64 families interviewed at 12 months. Nonetheless, despite some reservations regarding the costs, all the families used the equipment.

### Data collection

Following formal recruitment, there was an initial interview with every family wishing to participate ( $n = 79$ ) (any family member who wished to be present was included in the interview). Demographics and information needs were covered in this interview. At the same time, information was given to interviewees about the equipment and its installation; for example, the specification of the equipment, plus the need for a family to provide a desk or table close to a power supply and telephone point. Interviews were carried out at 3 and 12 months post-installation, looking at frequency of computer usage, and the advantages and disadvantages of the system.

### Data analysis

Quantitative analysis was conducted by the University of York using the SPSS computer program. Analysis of qualitative interview transcripts was based on the framework method (Ritchie & Spencer 1994), in which there are five steps: familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. From familiarisation (listening to and reading transcripts and interviewer's notes), the themes and major issues are identified (e.g. schoolwork and leisure) and then applied to the textual data. Charts are then devised (in the case of the present study, thematically, i.e. for each theme across all respondents). The final stage is the interpretation of the data.

## Results

### Demographics and initial findings

The total number of families diagnosed by 1 January 2000 was 88 and seven of these declined the provision of a computer because they already had one. Four families withdrew from the study because they moved from the area, or the boy died or was adopted. Seventy-nine initial interviews were carried out. These initial interviews were conducted with a carer, either a parent or a family relative. There were two exceptions where interviews were held with the young men themselves. Of these families, four had severe financial problems and one had no telephone land-line: these were then excluded from the study in order to avoid causing further monetary difficulties.

Seventy-two 3-month evaluations were carried out: it proved impossible to contact two families during the month of evaluation. Sixty-four 12-month evaluations were carried out. (Four late notifications were excluded because their equipment had not been installed for sufficient length of time and five families requested that their equipment be removed because they wished to purchase a more powerful computer. Such families were asked if they wished to continue being members of The Golden Freeway, but all excluded themselves and one boy died before the interview.)

The family members present at the 12-month interview varied. At some interviews, only one person was present (36 interviews mother only, three father only and two boy only), in others two family members were present (nine interviews mother and son, nine mother and father, and four father and son), and in one interview, mother, father and son were present.

### Sample characteristics

Seventy-four computers were installed. Six of the families had two boys with Duchenne muscular dystrophy, giving a total of 80 boys and young men participating in the project. Four were under 5 years of age, 34 were aged between 5 and 11 years, 30 were aged between 12 and 18 years, and 12 were aged 19 years or over. Forty-six were in mainstream schools, 23 were at special schools and 11 of the young men had left school.

There were 14 single parent families and 85 siblings from 55 families. At the commencement of the project, 30 families had prior access to the Internet; this was not necessarily from the home. The mean distance of families from Newcastle was 66.2 km, with a range of 1.3–229 km.

There were nine boys who did not use the standard keyboard and mouse. One young man had voice-activated software fitted to his computer, one used a roller ball, one used both the small keyboard with the touch pad incorporated and a mouse, and six used the small keyboard with the touch pad incorporated.

The following results are taken from the 3- and 12-month interviews.

### Usage of equipment and electronic services

Only one family did not perceive any advantages to owning a computer: this was a family who were moving out of the area and explained that, as a consequence, they were not prepared to attend a training session on using the computer.

There appeared to be substantial usage of the computer and electronic services in general (Table 1). There was no noticeable increase in computer usage or

**Table 1** Reported usage by participants responding after 3 and 12 months: (*n*) number; and (%) percentage

Type of use	Statistical significance ( <i>P</i> -value)*	Time after installation (months)	Frequency of use									
			Did not use		Less than once a week		Once a week		Two to five times a week		More than five times a week	
			<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Use of installed computer ( <i>n</i> = 62)	NS†	3	0	0	4	7	3	5	24	39	31	50
		12	0	0	2	3	5	8	22	36	33	53
E-mail ( <i>n</i> = 57)	0.077	3	14	25	22	39	9	16	10	18	2	4
		12	10	18	18	32	14	25	10	18	5	9
Internet ( <i>n</i> = 61)	NS	3	1	2	9	15	10	16	32	53	9	15
		12	3	5	6	10	13	21	23	28	16	26
Use for schoolwork ( <i>n</i> = 64)	0.016	3	38	59	2	3	5	8	17	27	2	3
		12	22	34	7	11	14	22	17	27	4	6

\* Wilcoxon signed ranks test.

† NS: not significant.

accessing the Internet between the 3- and 12-month interviews, although e-mail usage showed a slight increase. However, the video-conferencing facility proved to be less popular and only a minority of families used it. Those with Duchenne muscular dystrophy were the greatest users of the equipment.

### Major themes emerging from assessment of usage

The quotations in the following sections illustrate some of the themes which emerged from the *a priori* research issues (i.e. schoolwork, occupation and social isolation) and from the interviews (i.e. independence and relationships). These quotations are typical of the responses given and are carers' responses.

#### Schoolwork

It was anticipated that the boys would use the computer for schoolwork and such usage had indeed increased over the evaluation period (Table 1). It was being used for this purpose by 66% of interviewees at 12 months compared to 41% at 3 months. At the 12-month interview, 39 (61%) said that this was the greatest use of the computer:

He brings home a disk and does his homework on it and then they take it back to school. So it's helping him to do schoolwork and homework. He gets tired of writing at school so he finds he's doing more homework.

Parents of young children were also buying educational games in order to help their son at school:

... [H]e's into the learning games, which helps him a lot, and the teacher thinks it's wonderful that he will actually spend time at home on those kind of games and enjoy it at the same time.

The computer was used by siblings for their schoolwork, as commented on by five interviewees at the 12-month evaluation.

#### Occupation

It was expected that using a computer would create an occupation for the boys; this was so, and it also provided an interest and enjoyment:

It gets him out of bed. He gets into his chair to go on. He gets engrossed in it. It keeps him occupied.

And [ ... ]'s getting into it, he gets bored, but you can go on there and lose yourself for a bit when it's a rainy day or a dark night.

It was also perceived as advantageous as a family occupation by nine interviewees and as an occupation for siblings (seven interviewees). Having the boy occupied also gave mothers more time for themselves, as noted by 16 interviewees. It was mothers who were the main carers.

### *Independence*

Since Duchenne muscular dystrophy is progressive, as the boys approach adolescence they are increasingly reliant on their family for care (and particularly their mothers, as was emphasised by interviewees). However, having access to modern information technology can give them a degree of independence which can lead to improved self-confidence:

He can show his friends what to do and likes that. It has helped him a lot.

It gives him more confidence. Because he can do it himself.

He can come in and switch it on, the games bit, so probably for him it's been a boost to his confidence.

### *Extension of relationships*

An unexpected benefit was the extension of relationships. With the advent of a computer in the home, both fathers who did and those who did not know how to use such technology often worked with their son:

I think [husband] bonded a lot more with the boys because he was showing them games on the computer and everything ...

Mothers also enjoyed working with their son:

It's improved his concentration because it's something he can do and something we can sit and do together

Sibling relationships were extended in a number of instances. The boy with Duchenne muscular dystrophy could show his sibling how to operate the equipment; older siblings could help their younger brother:

The interaction with his brother is better ...

However, mothers of younger children often had to spend more time with the child since he did not yet have the ability to use the computer on his own. A typical comment about this was 'but I don't mind'.

### *Social isolation*

A computer provided a way of 'opening the world' for these young people; their horizons can be limited:

He doesn't go out a lot, so it's really been smashing for him, because he's stuck in the house all the time ...

Having a home computer meant that friends visited more often, thus reducing the social isolation experienced by the boy. Parents of older boys commented that they wished that The Golden Freeway had been available when their son was diagnosed:

It's much more youngster orientated and would allow them to develop a broader horizon. So they're not isolated. Isolation is something that greatly affects families.

The benefit of being able to be in contact with both extended family and friends was not unexpected, with

14 interviewees commenting on this as an advantage, but the enthusiasm of families, both boys and their parents, about using modern technology was a pleasure to observe:

Their father can keep in touch because he's away all of the time so he e-mails [ ... ] and he e-mails him back: the jokes come from work from his dad. [ ... ] has kept in touch with friends everywhere, Singapore, Korea.

E-mail was seen as a way of being aware of other families and of reducing social isolation:

You know that you're not the only ones going through all this horribleness, all the fighting for every single thing.

The availability of the medical team by e-mail was perceived as a benefit, with queries answered promptly.

### **Feedback and implication for future studies**

There were unexpected aspects from the team's point of view. They were initially unaware of some of the problems in creating an electronically linked community (e-community) amongst a group of people, some of whom had never switched on a computer:

For people who have not had a computer before, it's hard. When we got our first computer we were frightened to switch it on. It's just something to look at.

The majority of families became accustomed to 'surfing the net' and many of them would read their e-mails, but the idea of writing an e-mail was a problem:

The thing is, when you've got disabled lads like we have, you try not to encroach on other people ... I think it's just a matter of breaking the ice and maybe with the e-mail you could do that ... It's just getting round to it.

Families felt constrained because they had not met the person at the receiving end. However, one interviewee suggested that there are some families who do not want to be with other families who have a boy with Duchenne muscular dystrophy:

I don't think they want to be together ... I find a lot of them are like, 'I don't want to see anyone in a wheelchair,' and I find a lot like that ...

When asked what improvements could be made to the service offered by the project team, the majority of interviewees said no improvements were necessary; however, training was suggested. More training was required than had been anticipated and sessions were set up in Newcastle, Carlisle and Middlesbrough, with a total of 26 families (from 55 invited) attending a session. There were those who would have preferred one-to-one training, probably on a weekly basis for about 4 weeks, but unfortunately, the staff resources involved

were not available to do this. There were those who were happy to use the computer only for playing games. However, with the increasing use of computers and development of the e-culture in schools, the present authors expect that the children will help the parents.

The issue of cost was a difficult one to resolve. Interviewees felt that it was an inhibiting factor, and despite much research, no single Internet service provider offering free Internet access was found to be appropriate. Families tended to limit access to after 1800 h and weekends in order to maintain a check on the cost.

## Discussion

### Limitations

There are three main limitations to the present project: there was no control group, there were few responses from the boys themselves and there were no in-depth case studies.

### Child's responses

At the outset of the project, the researcher attended the Muscle Clinic in order to meet the families. It became immediately apparent that the majority of the boys were shy, referring all questions to their parents. Parents were also keen to hear the responses from their son; had interviews been carried out without the presence of the parents, it was felt that this would cause friction either between parent and child, or between parent and the project team. Therefore, the decision was taken on this occasion to use the parents' perceptions of their son's needs, but to acknowledge that the issue of the boy's perceptions would be addressed directly in any future study.

### In-depth case studies

From literature searches and meetings with health professionals, it was possible to understand some of the issues which might be raised. However, because the boys were all at a slightly different stage of the condition and because their backgrounds were very different, it was decided to interview all the families, again acknowledging that in-depth case studies should be considered in future studies. By interviewing all families, it was felt that this would provide a greater understanding of the most frequently raised issues.

### Exclusions

Five families elected to purchase a more powerful computer and excluded themselves because they no longer

wished to be a part of the project; despite gentle probing, the present authors were unable to establish the reason for this. However, this did have a positive aspect: it was as a result of receiving the computer and software that a family recognised the value of information technology both for themselves and their son. This probably would not have occurred at the time it did without The Golden Freeway.

### Feedback to The Golden Freeway team

The present authors believe that the relationships between team members and families was sufficiently robust to enable constructive criticisms to be offered, as evidenced by the suggestions made for improvements to the service, such as additional training and a user manual. However, in order to obtain feedback in an anonymous form, the help of the medical team was enlisted during the life of the pilot, but we received no additional feedback as a result.

### Family life

It was evident from the present study that family life was very important. Parents made huge efforts to stimulate, help and educate their son with Duchenne muscular dystrophy, leading to close ties between parent, boy and sibling. This importance has been highlighted elsewhere (Bach *et al.* 1991). It is known that family connectedness is a contribution to emotional well-being for adolescents with a disability (Wolman *et al.* 1993). It is also clear from the results of the present study that having a computer has drawn families together, creating or improving a father-son bond, and cementing sibling relationships.

Other parents of children with similar disabilities have been found to be a source of support for families (Petr & Barney 1993, Shank *et al.* 1999). An increase in e-mail traffic between families occurred during the project. As families have become more accustomed to their equipment and have had the opportunity to explore its capabilities, so they have been more willing to share their knowledge with other parents and also to ask questions of all families.

### Social isolation

Social isolation has been identified in a number of studies as problematic (Buchanan *et al.* 1979, Fitzpatrick *et al.* 1986, Cadman *et al.* 1987, Benony *et al.* 1996, Law & Dunn 2001). Families in the present study have observed that their son with Duchenne muscular dystrophy is less socially isolated as a result of having access to e-mail (and hence friends and family) and

because having a computer in the house acts as a magnet to his peer group. More than one parent commented that other boys did have a computer in their home, but it was to the boy with Duchenne muscular dystrophy's home that they tended to gravitate. Having friends visit more often meant less social isolation; it has been shown elsewhere that reduced interaction with peers can lead to social withdrawal (Thornes 2001).

### Development of an e-community

One of the greatest challenges within the project, one that was not anticipated by the team, has been creating an 'e-community'. Many of the boys with Duchenne muscular dystrophy and their siblings, particularly if older, used information technology in school, but for many parents, it was not part of their everyday world. Until families can develop the habit of checking e-mails on at least a weekly basis, information supplied in this format will not be accessed by them. However, comments made by parents suggest that many of them are now reading their e-mails even if they are not writing any. In a US study (Shank *et al.* 1999), it was suggested that daily struggles did form the content of some (unspecified number) discussion group messages via e-mail. In any future project, the development of an e-community through training sessions must have priority. It has been reported elsewhere that those with physical disabilities need increased levels of training in computer use (Pell *et al.* 1999). It was found in the present project that both parents and children required more training than was anticipated. A much greater training provision must be made in any future project; the use of a training video or CD-ROM is also an option which needs further exploration.

### The way forward

A management user group has been established for the families included in The Golden Freeway project, which will seek funding for replacement equipment and a formal means of representing the views of the users. Families not currently connected who have a newly diagnosed child are also able to take advantage of the facilities provided by The Golden Freeway. This pilot is now being extended to a nation-wide study. The Golden Freeway team is working in partnership with a number of other organisations across the UK with the aim of providing a computer, and Internet and e-mail connectivity to every family with a child with Duchenne muscular dystrophy. A further study has been funded in selected areas in the north of England to provide similar equipment to families who have a child with cerebral palsy.

### Conclusion

Families have proved cooperative, interested and appreciative of this project. They have been ready to offer genuine criticisms of The Golden Freeway which have proved invaluable in improving the service. There were a number of unexpected benefits which have proved illuminating; for example, relationships within the family have been extended; interest and enjoyment has been added to what is, for many, a confined life; independence has been improved; and self-confidence has been boosted. The project team has also learned from the project that: an e-community has to be developed from the earliest stages of the project; different levels of training must be instigated; and not all families will ever use equipment to its fullest extent. There have been the anticipated benefits for the boys with Duchenne muscular dystrophy, their siblings and families: the computer is used for schoolwork by all children; it creates an occupation; and social isolation is reduced both for the boys and for their families. It is clear that The Golden Freeway is welcomed by users as a source of information and support for those who have to contend with multiple difficulties throughout their son's life.

### Acknowledgements

Our thanks are due to all the families taking part in this study. We are grateful to The Children's Foundation for funding the project. We are also grateful for funding from the EU (DISTINCT project) and from SUNTele-Regions. Newcastle City Council has provided a considerable amount of support, and we are also grateful to the Department for Work and Pensions (formerly the Benefits Agency) for their involvement in the project. Finally, our thanks are due to the staff of the University of Newcastle, particularly our colleagues in the Department of Child Health and the Faculty of Medicine Computing Centre, and to the Social Policy Research Unit at York University.

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